

Ontario Provincial Framework for Palliative Care

Acknowledgements

Developing the Provincial Framework for Palliative Care would not have been possible without the participation and insight provided by key organizations, groups and individuals. The Ministry of Health would like to acknowledge the leadership of Ontario Health and the contributions from many stakeholders and Indigenous partners, including people living with serious illnesses and members of their families, health care providers, caregivers, long-term care homes, researchers, as well as other hospice and palliative care organizations in Ontario. Their input and the deeply personal stories they shared helped shape the Framework. Contributors, stakeholders, and Indigenous partners shared their experiences with care – including in a range of cultural and linguistic contexts – and a diversity of opinions. For these perspectives, we are very grateful. The following document reflects those insights and opinions.

Message from Christine Elliott, Deputy Premier and Minister of Health

With the passage of the *Compassionate Care Act, 2020*, the Ontario government is continuing to improve access to high-quality palliative care for individuals and families across the province.

In many ways, palliative care (which includes end-of-life care) exemplifies care that is centred on people. It focuses on improving the quality of each individual's life, provides integrated and holistic care for individuals, their families and caregivers and ensures that they have access to the supports they need when facing illness, death, grief, and bereavement. It also helps to highlight how death, dying, grief, and bereavement are all part of life and how everyone can benefit from advance conversations about planning and goals of care.

The introduction of the Provincial Framework for Palliative Care comes at an important time for Ontario. Over the years, the province's health care system has become fractured and disconnected, often making it difficult for people to access the care they need. Our government made a commitment to build a better-connected health care system focused on the needs of patients, and strengthen the long-term care home system. The COVID-19 pandemic has only strengthened our resolve, as we build on

important lessons learned that will support our efforts to improve the lives of people across the province.

As we undertake this important work to improve access to high-quality palliative and end-of-life care, we also continue to break down long-standing silos through a shift to a better connected, person-centred and inclusive health system that will support Ontarians throughout their entire health care journey. Ontario Health Teams are a new approach to health care that brings together health care providers as one collaborative team and ensures Ontarians experience easier transitions through their care journey, including palliative and end-of-life, with one patient story, one patient record, and one care plan, while providing individuals, families and caregivers help in navigating the public health care system, 24 hours a day, 7 days a week. Ontario Health Teams will also partner with other care providers, including palliative and end-of-life providers, as part of this commitment to integrated care. These efforts are part of our comprehensive plan to create a health system that will address the unique needs of every person from the moment they are born, to the moment they pass.

By continuing to build a more connected, person-centred, and inclusive health care system, we are committed to working with our health system partners to ensure effective palliative care approaches are integrated across different care settings, in a manner that puts individuals at the centre of each decision. Together, we are ensuring Ontarians receive the care, dignity and respect they deserve in every stage of their lives.

As we embark on this effort, we need to focus on areas that matter most to individuals, families and their caregivers. The shared experiences and observations expressed through our engagements have informed our efforts to ensure that we're building a system that meets the needs of individuals across the whole province. It is imperative that their cultural values and personal preferences be voiced, understood, and respected when discussing goals of care and treatment options.

This Framework will guide future work to ensure that every Ontarian who needs palliative care – whether they are in their own residence, hospital, a long-term care home, a retirement home, or in another community setting – has better access to high-quality services, including in the final stages of life.

Ontario is committed to developing a more integrated health care system to better serve Ontarians at every stage of life, with smooth transitions between points of care and improved responsiveness and patient experience. The Ontario Health Team model is the foundation of an integrated system. Within this model, health system partners (including, as appropriate, hospitals, long-term care homes, physicians, and home and community care organizations) support their clinicians and care providers across care settings to work as one coordinated team.

The Provincial Framework for Palliative Care will support the efforts of Ontario Health Teams as they work to deliver high-quality palliative care and collaborate with their partners to support Ontarians in all care settings.

On behalf of all Ontarians, I extend my appreciation and gratitude to all of those who participated in the discussions that informed the Provincial Framework for Palliative Care. The expertise, perspectives and personal stories shared provide us with a guide for the work ahead and underscore why this work is so important for our communities, individuals, and families. And a special thanks to my colleagues, Mr. Sam Oosterhoff and Ms. Natalia Kusendova, who assisted with facilitating these discussions, for their dedication and leadership.

Introduction

The Compassionate Care Act

The [Compassionate Care Act, 2020](#) (CCA) received Royal Assent on December 2, 2020. The purpose of this Act is to develop a framework to ensure that every Ontarian has access to high-quality palliative care. The Minister of Health was tasked with developing a provincial framework that will support improved access to palliative care provided through hospitals, home and community care, long-term care homes and hospices, that among other things,

- a) defines what palliative care is;
- b) identifies the palliative care training and education needs of health care providers as well as other caregivers;
- c) identifies measures to support palliative care providers;
- d) identifies research and common data elements on palliative care;
- e) identifies measures to facilitate equitable access to palliative care across Ontario, with a focus on underserved populations;
- f) identifies measures to facilitate consistent access to palliative care across Ontario;
- g) takes into consideration existing palliative care frameworks, strategies and best practices;
- h) takes into consideration and supports the needs of specific patient populations, including pediatric patients; and
- i) leverages the expertise and capacities of other key partners in Ontario's health system, such as the Ministry of Long-Term Care, Ontario Health, Ontario Health Teams, and other providers and organizations.

The Minister of Health is required to prepare a report setting out a provincial framework for palliative care, to be tabled in the Legislative Assembly of Ontario one year after the Act comes into force. Three years after this report is tabled, the Minister of Health is required to prepare a subsequent report on the state of palliative care in Ontario, also to be laid before the Legislature.

The Act requires the Minister to consult with palliative care providers, other relevant provincial ministries, the federal government and any other persons or entities to inform the development of the Provincial Framework for Palliative Care (the "Framework"). In collaboration with the Ontario Palliative Care Network (OPCN), the Ministry's principal advisor on palliative care, the approach to develop the Framework, included:

- reviewing existing guidance documents from the provincial, national, and international levels, and other key palliative care literature to extract content and address the elements of the Framework. Many of these documents reflect extensive stakeholder and partner engagement with providers, individuals, and their families, including engagement from diverse and underserved populations;
- incorporating content gathered from regular and ongoing engagements with the Ontario Palliative Care Network's regional and provincial partners;
- conducting four strategic consultations from June to September 2021 to engage stakeholders, partners, and the Minister's Patient and Family Advisory Council on the important issues in the sector; and
- conducting 14 separate technical consultations from May to August 2021 to seek additional stakeholder feedback on key actions to improve palliative care in Ontario.

PART I – Background

What Is Palliative Care?

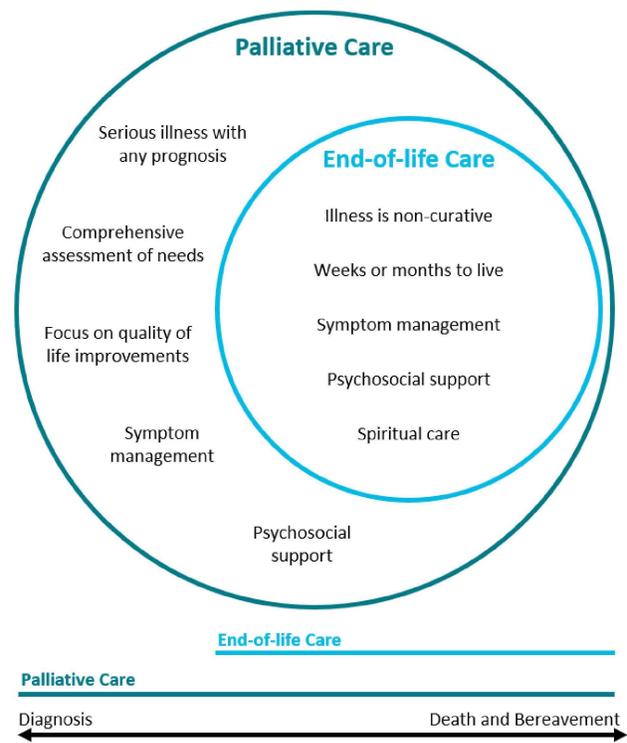
Palliative care is an approach to care that aims to relieve suffering and improve the quality of living and dying for every person with a serious illness*. It strives to help the individual and their family/caregiver(s) to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage end-of-life choices and the dying process;
- cope with loss and grief;
- treat all active issues and prevent new issues from occurring; and
- promote opportunities for meaningful and valuable experiences, and personal and spiritual growth.ⁱ

This definition is aligned with those of both the Canadian Hospice Palliative Care Association and the World Health Organization. It reflects the shift in practice away from focusing solely on end-of-life care, and towards a broader, more holistic approach that can begin as early as diagnosis of a serious illness.

Palliative care focuses on the individual, their family, and caregivers and can be complementary alongside other treatments throughout the illness trajectory, through to end-of-life and bereavement. Integration of palliative care can be helpful regardless of an individual’s goals of care, whether they focus on curing the illness, prolonging life, or maximizing comfort. A comprehensive, holistic assessment allows health care professionals to determine the physical, psychological, social, linguistic, cultural, ethical, and spiritual needs of the individual and their family or caregiver and the services required to meet those needs.

*** What is a serious illness?**
Serious Illness is defined as “A health condition that carries a high risk of mortality and either negatively impacts a patient’s daily function or quality of life or excessively strains the caregiver.”ⁱⁱ



History of Palliative Care in Ontario

Palliative care emerged as a new type of health care service in Ontario in the late 1970s. Through the 1980s there was continued growth of palliative care programs across Canada, though variability remained in the quality and availability of programs. Through the 1990s and into the early 2000s, some initiatives emerged to try and standardize palliative care across the province.

In 2010, the Quality Hospice Palliative Care Coalition of Ontario ('the Coalition') was formed to bring together organizations, universities and research institutions working at a provincial level in the palliative care field to ensure quality palliative care for Ontarians. In 2011, the collaborative work of the Coalition resulted in the Declaration of Partnership and Commitment to Action: Advancing High Quality, High Value Palliative Care in Ontario (the Declaration), a document that outlines a common consensus on a vision and plan for palliative care in Ontario. More importantly, the Declaration identified key priorities, and commitment from various partners to both individual and collective actions needed to achieve them.

The Provincial Hospice Palliative Care Steering Committee (the Steering Committee) was formed in 2012 to carry out the vision outlined in the Declaration. In October 2014, the Steering Committee reviewed its progress and noted that the key gaps in palliative care identified in the Declaration still existed. The Office of the Auditor General of Ontario (OAGO) also released its audit of palliative care around the same time outlining similar gaps. Recognizing the need to enhance accountability for the priorities outlined in the Declaration, the Steering Committee recommended the establishment of the Ontario Palliative Care Network.

In 2016, the Ontario Palliative Care Network was established by the Ministry of Health (at that time, the Ministry of Health and Long-Term Care), and was given the mandate to:

- be a principal advisor to the Ontario government on quality, coordinated hospice palliative care in the province;
- be accountable for quality improvement initiatives, data and performance measurement, and system-level coordination of hospice palliative care in Ontario; and
- support regional implementation of high-quality, high-value hospice palliative care.

At the provincial level, the Ontario Palliative Care Network is supported by a Secretariat that enables and executes the mandate, and the staff are housed at Ontario Health.

Established in 2019, Ontario Health has integrated a number of provincial agencies to support health system oversight and integrated delivery. At the local level, Regional Palliative Care Networks were established. The Regional Palliative Care Networks across Ontario consist of various organizations and professionals who are stakeholders in palliative care. They provide leadership and structure to develop a comprehensive, integrated and well-coordinated system of palliative care for individuals and their families in their respective region(s).

Current State

Service Delivery and Organization

In Ontario, palliative and end-of-life care is provided in a variety of settings, and by a range of professionals working together across the health care system. Physicians, nurses, social workers and other health care providers offer care through clinics, hospitals, residential hospices, and home visits, including individual residences, long-term care homes, retirement homes, assisted living, and supportive housing. Given that many individuals residing in long-term care homes have serious illnesses, and most remain there until end-of-life, palliative care plays an essential role in enhancing overall care and quality of life for residents.

In the community, care providers often collaborate as interprofessional teams with varying levels of primary care involvement, supported by a range of palliative care specialists or experts such as the Regional Palliative Care Networks. Additionally, family members, caregivers, and volunteers provide a sizable amount of care for all individuals with palliative needs.

Expertise in pediatric palliative care currently exists almost entirely within the five pediatric tertiary centres (CHEO, Children's Hospital - London Health Sciences Centre, Kingston Health Sciences Centre, McMaster Children's Hospital - Hamilton Health Sciences and The Hospital for Sick Children). Due to the relatively small number of children with pediatric palliative care needs, centralized expertise is necessary to maintain clinical competencies and comfort. As a result, most children must travel, sometimes great distances, to receive care at these institutions, and many will also die there, often in critical care units, away from the support of friends and family.

Funding and Health Human Resources

Palliative care is funded in a variety of ways in Ontario, such as provincial home care budgets or other health service delivery budgets. These arrangements often result in regional variations in funding to support comprehensive care. For example, residential

hospices are funded in part through charitable donations which can be inconsistent and challenging for some communities.

In the community, when people choose to receive care in the home and/or die outside of acute care, families and caregivers must often assume out-of-pocket costs (travel, overnight accommodations, privately funded services, and so forth). As a result, hospital-based care often becomes the default option, particularly for end-of-life care when individuals, their families, and caregivers sometimes struggle to get the supports they need in the community.

In long-term care, residents may have access to palliative care, but access and approaches to care can differ, as some homes might not have the resources to meet residents' needs including appropriately trained staff. Similar to in the community, when supports are not available, hospital-based care often becomes the default option, particularly for end-of-life care.

Approximately 58,000 seniors live in retirement homes in Ontario. Unlike long-term care homes, where resident accommodations are subsidized and health care is provided directly, these seniors rent their homes and purchase care or receive support through the publicly funded system for home care and other services. These seniors also access palliative care through their primary care providers, other community programs, and hospitals. In order to remain in their home at the end of life, these seniors may require supports similar to individuals that prefer to die at home in private dwellings or apartments.

Quality Improvement and Performance Measurement

In an effort to improve access to palliative care services in Ontario, the Ontario Palliative Care Network reports and monitors system and support level palliative care indicators. Key indicators are represented at provincial, regional, and sub-regional levels. Measurement can identify opportunities to improve the use of system resources and, more importantly, identify areas for improving the quality of care and subsequently, quality of life.

Indicators can highlight where attention is required to advance effective practices, including models of care and service access. For example, understanding the proportion of people receiving home care at the end-of-life and dying at home is useful for measuring palliative care quality in the health system. In 2019, 35.1 per cent of Ontarians who died in the home or in the community, received palliative home care or a

physician home visit(s) in their last 90 days of life¹, compared to 30.8 per cent in 2011. There have been negligible changes to the province's performance on this indicator since 2015. This trend suggests that the ministry's efforts to deliver integrated care through Ontario Health Teams should include plans to better connect Ontarians with the palliative care they need, in their preferred setting.

Additionally, tracking the percentage of deaths that occur in hospitals can help determine whether access to palliative care in the community is improving, as most people prefer to die at home. In 2019, 51.4 per cent of deaths occurred in hospital³, which is down slightly from the 51.8 per cent average of deaths in hospital over the past four years. While performance on this indicator is moving in the right direction, the trend demonstrates that further efforts are required to support individuals in the community – where they would prefer to receive care – so that institutional services are focused on those who need them most.

Factors Driving the Need for a Framework

There are a range of factors driving the need for a framework, including inconsistent access to palliative care, learnings from the care experience during the COVID-19 pandemic, and an opportunity to influence and leverage health system integration for improved palliative care access and delivery.

Palliative care is appropriate for individuals with any type of serious illness, to prioritize quality of life. However, individuals diagnosed with cancer are three times more likely to receive palliative care than others, both in hospital and at home. Additionally, while people of all ages may need palliative services, most of those who use them are elderly. In Ontario, the number of individuals aged 65 and over is expected to almost double from 2.6 million (17.6 per cent of the population) in 2020, to 4.5 million (22.2 per cent of the population) by 2046. The growth in the share and number of this age group increases over the 2020–2031 period as the last of the baby boomers reach age 65. As Ontarians age, and more chronic illnesses are identified, the demand for high-quality palliative care will increase.ⁱⁱⁱ

Evidence and advice collected over the last several years also suggest that there is room to improve the health system's responsiveness to Ontarians' needs.

- In 2014, the Auditor General^{iv} reported that while Ontarians would prefer to die at home, most spent their final days in hospitals, likely because the services

¹ Data obtained from the OPCN's System Level Measures Report Fiscal Year 2019/20. Note that this report is not publicly available.

available in the community could not meet health care needs, or goals of care were unidentified.

- For individuals who do receive palliative home care, almost all have family or friends helping to care for them, making it possible to stay at home.^v
- It is reported that about one in three caregivers experience symptoms of distress and could benefit from caregiver supports.^{vi}
- There are also significant barriers to accessing palliative care for certain communities. First Nations communities, for example, have noted that the availability of palliative services on reserve varies widely among their communities, with some having little or no access to palliative services. We also know that – even when palliative care is available to First Nations, Inuit, and Métis peoples – that it is challenging to access culturally safe services.^{vii}
- Caring for terminally ill patients in an acute-care hospital is estimated to cost over 40% more than providing care in a hospital-based palliative-care unit, more than double the cost of providing care in a hospice bed, and over 10 times more than providing at-home care.
- In April 2021, the independent Long-Term Care COVID-19 Commission outlined recommendations for long-term care homes to ensure access to palliative care for all residents. The report included recommendations that the Ministry of Long-Term Care implement best practices for end-of-life care, ensure all homes have ready access to skilled palliative clinicians, and update the Long-Term Care Home Design Manual, 2015, to facilitate the effective provision of palliative care.

Palliative care delivery has typically been organized at the local level, predominantly driven by grassroots initiatives and local networks of providers. This has led to groups of palliative care programs that respond to local needs by building on existing resources rather than meeting a standardized model. In addition, despite the benefits of these local programs, disparities in access still exist.

Ontario Health Teams will work with local providers to establish an equitable approach to care delivery and assist all Ontarians with accessing palliative care services regardless of where they live.

Summary of Consultation Findings: What We've Heard

To inform the development of the Framework, a series of consultations were held to engage in conversations about priorities to advance palliative care. These consultations included community partners and stakeholders, including advisors from hospitals, primary care, long-term care homes, hospices, home and community care providers, health care associations and organizations, as well as individuals and their families and caregivers from communities around the province.

The engagements reinforced previously identified palliative care priorities. The following key themes emerged from those engagements.

Integrated palliative care should be available throughout a person's illness, and across care settings

Individuals with palliative needs are not always identified early enough in their disease trajectory. Only some health care professionals acknowledge the need and importance of introducing a palliative approach to care early in the course of the illness. Additionally, many health care professionals continue to equate palliative care with end-of-life care, and there is also often a lack of integration between palliative care programs and services for chronic disease management. This is especially true for adolescents and young adults with serious illnesses, who have complex needs and require care that may be different from the approaches used with pediatric and adult populations. While a systematic approach is required to coordinate transition planning for adolescents and young adults, this is not always achieved and can result in fragmented care. This can create barriers to providing complete care for adolescents and young adults from diagnosis of serious illness through to death and bereavement.

Additionally, while the current system values caring for individuals where they live, we heard that more needs to be done to improve access to high-quality palliative care for residents in long-term care homes. Long-term care homes are required to ensure that every resident receives end-of-life care in a manner that meets their needs. We heard that long-term care homes face operational barriers that make it a challenge to provide high-quality palliative care.

Prioritize equitable access for all Ontarians

Participants told us about the importance of ensuring all individuals have access to culturally appropriate and safe palliative care at the community level, including those from urban, rural and remote communities, First Nations, Inuit and Métis communities, and various cultural, faith and linguistic groups, vulnerable populations, and people with disabilities. Disparities in access to palliative care are faced most often by those living in rural and remote areas, with lower socioeconomic status, and/or underserved populations, which includes homeless and/or vulnerably housed people, First Nations peoples living on reserve, visible minorities, and individuals who identify as being a member of the 2-Spirit (Two-Spirit), lesbian, gay, bisexual, trans, queer, questioning, intersex, and asexual (2SLGBTQQIA+) community. In many cases, providers may not be prepared to respond adequately to the needs of culturally and linguistically diverse populations.

For First Nations people living on reserves, there are unique challenges to access caused by geography and jurisdictional roles and responsibilities. There are very limited programs that support access to medical equipment and supplies for those living on reserve (e.g. Non-Insured Health Benefits or NIHB administered by Indigenous Services Canada). There can also be challenges when an individual receives care through a provincially funded hospital and then transitions to care in the community, where services may be limited (i.e. 9am-5pm Monday to Friday) and funded federally with varying eligibility requirements. Shortages of health human resources in fly-in communities are particularly challenging.

Although there is a large Francophone population in Ontario, individuals are not always able to receive health care services in their language of choice. Increasing access to French language palliative services was a key message during our discussion with stakeholders. Highlighted considerations include increased access to French virtual care providers, and ensuring educational programs and materials are also offered in French with terminology that is consistent with Francophone understanding of palliative concepts.

Caregiver and bereavement supports are crucial parts of the palliative continuum of care

Informal caregivers offer valuable support to those receiving palliative and end-of-life care. Individuals often rely on family members or friends to augment the services provided by the health system to ensure all needs are met and advocate for what is missing. At each discussion, it was highlighted how important caregiver supports are in order to sustain these informal services and prevent burnout. Caregiver respite services are crucial if individuals are going to spend their final days at home or in the community. These brief breaks allow caregivers an opportunity to recharge and manage their own obligations.

We also heard of an increased need for bereavement support. Palliative care goes beyond end-of-life support and continues with caregiver bereavement which can present itself as acute or chronic. This gap was further realized during the pandemic, as a large number of caregivers reported being left to process their grief in isolation. In the immediate future, many Ontarians may experience more complex grief because they were unable to visit their loved ones before the time of death, due to public health measures.

Children with serious illnesses have unique needs and require a different approach

When a child and family are challenged by a serious illness, the integration of pediatric palliative care can be helpful regardless of the goals of care, whether they are focused on cure, prolonging life, or maximizing comfort. While pediatric palliative care and adult

palliative care share many similarities there are just as many differences, resulting in unique barriers and disparities for children with palliative care needs that require special attention to resolve.

Delivering palliative care to children tends to be more complex than for adults. Additionally, the small number of children requiring palliative care distributed across a vast provincial geography requires a different approach from how adult palliative care is organized and delivered. A successful provincial approach to pediatric palliative care requires a regional “hub-and-spoke” model that leverages specialist teams, affiliated with pediatric tertiary centres. Implementation of the “hub-and-spoke” model has had some success in areas where hubs have more fulsome pediatric palliative care teams, such as in Toronto and Hamilton; however, insufficient resources have been a barrier to the implementation of this model of care across Ontario. Specialized expertise is essential to support those providing care in community hospitals, outpatient clinics, hospices and individual residences, either through direct care or through consultation and mentorship.

Family caregivers and parents who experience the early death of a child may be unable to cope with the loss. Furthermore, children have different care needs based on age and developmental stage. When a child lacks the capacity to decide for themselves, their parents/guardians will have to make decisions on their behalf according to their best interests, during highly stressful times. While the expertise and resources required to provide high-quality pediatric palliative care are significant, the demand in the larger context of palliative care across Ontario is small. Though some progress has been made to improve availability and access to pediatric palliative care in Ontario in recent years, inequities persist.

Barrier-free communication can increase coordination between specialized palliative care providers and community-based providers, including caregivers

We heard that collaboration between professionals and organizations can optimize health care outcomes and the experience of the person receiving care. Palliative care is an interprofessional approach to care. For any given individual living with a serious illness, their experience may involve many transitions in care and service delivery.

Stakeholders agreed that there is a pressing need for digital solutions that can support care delivery and coordination across these transitions. Tools to support communication between care settings (such as primary care, hospitals, home care and long-term care homes), will not only reduce care fragmentation but also the need for individuals and their loved ones to repeat their stories to each provider.

Early introduction of advance care planning (ACP) / goals of care (GOC) discussions can improve quality of life

An early introduction of ACP and GOC discussions help identify an individual's values, preferences, and wishes so they can inform care decisions. Resources are available to support these discussions with individuals and families.

It was clear in our consultations that planning and discussions need to take place with all individuals diagnosed with a serious illness, to ensure the care they receive aligns with their preferences.

These planning discussions are generally among individuals and their families and health care providers to help inform substitute decision-makers of their loved ones' wishes and values relating to the services delivered to them, including through to last stages of life.

However, we also heard that ACP and GOC discussions were often taking place too late, and that many clinicians feel unprepared, or lacked the skills required to have them. While initiating these discussions can be difficult, they are nonetheless crucial. A clear articulation of an individual's wishes and preferences can help reduce undesired interventions and improve the individual and the family's quality of life and overall experience. Some participants went further to suggest that ACP initiatives could be part of broader public health campaigns to benefit all Ontarians.

Increased awareness for providers and the public on how to navigate the system

We heard that family members, caregivers, and providers still have a hard time navigating the palliative care system. There is a widespread perception that the system is not designed to make the final stages of life as easy as possible. As the government transforms Ontario's health system — including the expectation that Ontario Health Teams work together to understand a person's full health care history, directly connect individuals to different types of care, and help them navigate the health care system 24/7 – care must be taken to ensure continuity of care for individuals receiving palliative care.

Foundational education for all providers with opportunities for specialization

Participants discussed the importance of ensuring that providers have foundational knowledge of palliative care, notwithstanding the need for access to specialized professionals for mentorship and consultation. Some organizations are utilizing professional development programs to provide active learning opportunities focused on best practices in caring for individuals with serious illnesses. More resource-based

education materials updated on the latest best practices could support providers in the workplace and facilitate better transitions between providers.

Reliable access to health human resources across all sectors

We heard about the crucial role that front-line health care providers play in supporting individuals in their homes; however, there are significant concerns about the availability of health human resources in various sectors across the province. A range of issues – including compensation and working conditions – have resulted in recruitment and retention challenges. Participants noted that it will be necessary to build capacity in the community, in order to meet the needs of all Ontarians with serious illnesses.

The COVID-19 pandemic has increased strain on the health system and further challenged access to palliative care

With the continuing spread of the virus, more individuals have been receiving palliative care services in their home – and remaining at home for their final days and weeks of life. Changes in visitation policies either prohibited or limited the ability of loved ones to be at the bedside in hospitals, palliative care units, and hospices. Community palliative care providers were working with fewer staff due to public health measures and overall health human resource shortages.

To address some of these challenges, Ontario has relied heavily on virtual care to connect providers – including those providing palliative care for individuals. Stakeholders agreed that digital resources, such as virtual care visits, can be leveraged to improve access to care, particularly in rural and other hard-to-reach communities. We also heard that these resources and services need to be broadly accessible to individuals with a variety of linguistic, cultural, spiritual, and other needs.

Provincial Efforts to Support Improved Access to Palliative Care

Over the years, the government has taken action to improve access to and the quality of palliative care. Understanding that investments are needed across multiple sectors (i.e., home and community care, primary care, acute care, long-term care, etc.) the Ministry is working with numerous stakeholders to achieve high-quality palliative care for all Ontarians. Dedicated provincial funding in hospice expansion and palliative care quality improvement initiatives have increased from \$67 million in 2018 to over \$74 million in 2021. Some investments in recent years that assist in the delivery of palliative or end-of-life care include:

- Expansion of residential hospice services through operational and capital funding investments including over \$40 million in capital funding since 2018, to build more

than 200 residential hospice beds across the province. When these beds open, the government will provide over \$23 million each year in operational funding for nursing, personal support, and other services delivered to individuals in these beds.

- Investing up to \$23 million in eligible hospice residences across the province in 2021 to address additional costs associated with COVID-19, including the procurement of personal protective equipment.
- Investing over \$5 million between 2016 and 2020 on educational and training resources for providers, caregivers, individuals, and families. Some notable resources are highlighted in the Framework.
- Establishing the Ontario Palliative Care Network in 2016 to act as the Ministry's principal adviser for quality, coordinated palliative care in Ontario. The Network is accountable for quality improvement initiatives, providing system level coordination, and supporting regional implementation of the palliative care initiatives.
- Investing \$1 million annually in the Ontario Centres for Learning, Research and Innovation's Communication at End-of-Life Education Fund to enhance long-term care home staff's skills and competencies in palliative and end-of-life care for residents and their families.
- To better recognize the important role played by caregivers, investing in expanded caregiver supports, including caregiver training and education, as well as investing up to \$7 million in the Ontario Caregiver Organization for 2020-2022 to expand the reach of the Organization and its resources across the province, ensuring caregivers are supported no matter where they are located.
- Investing over \$1.3 billion for the personal support worker wage increase to help stabilize staffing levels and support frontline health care workers during the COVID-19 pandemic. The wage enhancement extended to over 158,000 workers during the pandemic, who deliver publicly funded personal support or direct support services in hospitals, long-term care homes, home and community care, and social services.
- Piloting the Paramedics and Palliative Care program in 2021, which allows eligible individuals receiving palliative care in 33 communities to receive assistance from a trained paramedic to help avoid unnecessary emergency department visits.
- Introduction of Ontario Health Teams, which are a new approach to health care that brings together health care providers as one collaborative team and ensures patients experience easier transitions with one patient story, one patient record and one care plan that is shared between health care providers. This will facilitate the integration of effective palliative care approaches across different care settings.

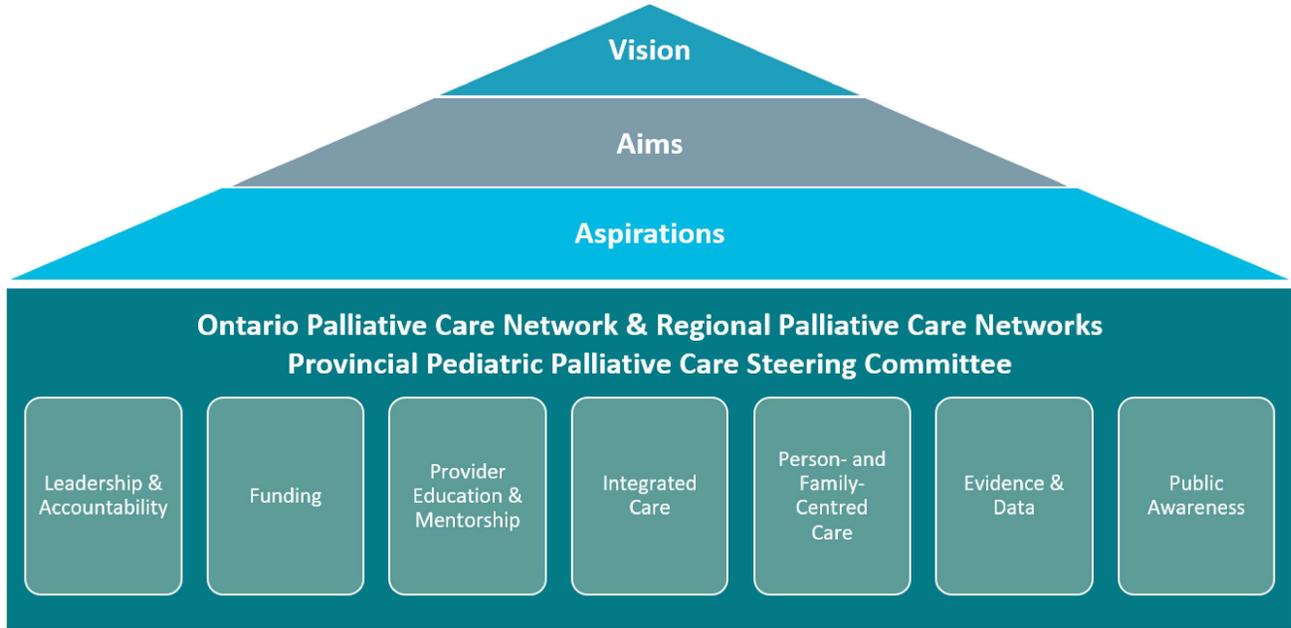
The Ministries will continue to collaborate with partners across the health system, as well as individual Ontarians receiving palliative care, their families, and communities, to improve access to palliative and end-of-life care.

PART II - The Framework for Palliative Care in Ontario

Overview of The Framework

The *Compassionate Care Act, 2020* calls for the development of “a provincial framework designed to support improved access to palliative care.” This Framework is a multipurpose tool that aims to improve how palliative care is planned, delivered, and evaluated in the province. It can be utilized for palliative care service planning, delivery, and to guide future policy and program design, as well as assist in funding decisions to improve palliative care for all individuals who would benefit in Ontario.

The Framework includes a number of different components, as depicted in the figure below. Seven building blocks form the foundation of the Framework.



Vision

The central vision of the Framework is as follows:

Adults and children with a serious illness, as well as their families and caregivers, will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to help them live as they choose and optimize their quality of life, comfort, dignity, and security.

Aims

The vision is supported by an adaptation of the Institute for Healthcare Improvement's quadruple aim^{viii}:

1. improving the individual, family, and caregiver experience by delivering high-quality, seamless palliative care;
2. improving the provider experience, by ensuring they are supported and prepared to deliver high-quality, seamless palliative care;
3. improving population health by maintaining and supporting the quality of life and health of people with serious illnesses, as well as their families and caregivers; and
4. reducing health system costs by delivering more cost-effective care and creating a continuously self-improving system.

Aspirations

The Framework intends to improve the quality of living and dying for individuals, their families and caregivers, who are facing a life-limiting or serious illness by aspiring to achieve the following:

Individuals and their families and caregivers receive person-centred care in their preferred locations, where possible – Holistic and person-centred care ensures the unique needs of the individual are addressed across all domains, and that their wishes and preferences, along with their cultural and spiritual values direct the care they receive. As a result, individuals are less likely to receive unwanted or unnecessary treatments and are more likely to have higher levels of satisfaction and trust within the health care system.

Care providers feel supported and prepared to meet the needs of individuals, families, and caregivers – Palliative care is most effectively delivered by providers who are skilled in all aspects of the discipline. Providers who possess the appropriate communication skills, knowledge, and attitudes about the model of care have a positive influence on a person's experience with palliative care.

Care is timely, coordinated and delivered by an interdisciplinary team – Integration of palliative care, occurring as early as diagnosis of a serious illness, helps to enhance quality of life for the individual, their family, and caregivers throughout the illness trajectory, from diagnosis to end-of-life. Coordination of team-based, integrated care encourages continuity of care and leads to improved pain and symptom management, optimal psychosocial outcomes, as well as fewer hospitalizations and emergency department visits.

Access to palliative care is equitable – Equitable palliative care enables all individuals to live well with a serious illness regardless of where they reside or receive care, and irrespective of their race, religion, age, gender, culture, language, sex, sexual orientation, income, or diagnosis.

Seven Building Blocks

The following seven building blocks are the focus areas of the Framework and outline the goals and actions required to achieve the aspirations and shared vision for palliative care in Ontario. The goals and actions were informed by the various consultations that took place, and are intended to build on and leverage the considerable work that has been done by various palliative care stakeholders in the province.

1. Leadership & Accountability

Effective and efficient palliative care service design and delivery requires strong and visible leadership. Accountability models and structures can drive consistent access and delivery of palliative care across the province and ensure value for money. Key accountability mechanisms include performance metrics, policies, guidelines, standards, and funding.

Goals
<ol style="list-style-type: none"> 1. Gaps in leadership and accountability for palliative care in Ontario are identified. 2. Accountability mechanisms for palliative care in Ontario are developed/refined. 3. Clear leadership and accountability structures are in place to drive high quality palliative care in Ontario.
Next Steps
<ul style="list-style-type: none"> • Identify existing accountability levers and structures driving effective and efficient service design and delivery of equitable and integrated palliative care. • Clarify and adjust provincial and regional service providers’ roles and responsibilities to support an integrated approach to palliative care services, in alignment with the implementation of Ontario Health Teams and other measures to improve individuals’ experiences, including resident experiences in long-term care homes.

- **Leverage resources and expertise from health system partners such as the OPCN to facilitate implementation of recommended provincial palliative care guidance and to strengthen provincial and regional accountabilities.**

Examples of existing resources:

- **Ontario Palliative Care Network (OPCN)**
The OPCN’s mandate and relationships with stakeholders means it is well positioned to lead system changes needed in palliative care. It works closely with various organizations and professionals working towards a well-coordinated palliative care system for individuals and their families in their region. The OPCN’s regional teams play a role in aligning service providers to provincial direction by mobilizing stakeholders while leading implementation of quality improvement approaches.
- **Provincial Pediatric Palliative Care Steering Committee (PPPC-SC) and the Regional Implementation Working Groups (RIWGs)**
The PPPC-SC includes diverse representation from provincial level associations and community organizations, resulting in unique PPC expertise that ideally positions this group to continue working closely with the OPCN to inform provincial direction for PPC. The five RIWGs across Ontario can support alignment and implementation efforts by working with local PPC providers to identify service gaps, drive integration and innovation, and share PPC best practices.

2. Funding

Investments in palliative care can enable sustainable and equitable access to supports and services for Ontarians. Funding allocations should consider support for health human resource capacity needs, access to equipment and supplies across care settings, as well as access to psychosocial, spiritual, mental health, grief and bereavement services, education, and mentorship.

Goals
<ol style="list-style-type: none"> 1. Current palliative care funding and costs are reviewed across all care settings, including at the provincial, organizational, and individual levels. 2. Costs to achieve an integrated model of care for palliative care in the hospital, long-term care home, and home and community care settings are identified, and gaps in funding are assessed.

<p>3. Funding allocation is equitable and supports coordinated palliative care across care settings and demographics.</p>
<p>Next Steps</p>
<ul style="list-style-type: none"> • Leverage the care pathways outlined in the models of care for palliative care to assess the associated costs, and gaps in current funding models across care settings. • Remove barriers to delivering care in current funding models. • Review structures and/or terms and conditions of existing funding to incentivize high-quality services. • Continue to assess unique needs across different care settings prior to allocating funding to enable appropriate and equitable distribution of services, reflecting Ontarians' needs.

Example of existing resources:

- **Canadian Society of Palliative Care Physicians (CSPCPs) Staffing Model for Palliative Care**
A working group within the CSPCP refined and validated a recommended staffing model to provide a systematic way for programs to determine required staffing².

3. Provider Education and Mentorship

Healthcare providers across care settings benefit from the necessary knowledge and skills to deliver high-quality palliative care when and where it is needed. Education and mentorship opportunities build palliative care capacity, and ensure providers have the competency to identify those who would benefit from a palliative care approach.

<p>Goals</p>
<ol style="list-style-type: none"> 1. Education and mentorship needs of health care providers are identified. 2. Providers have equitable access to education, mentorship, and tools to meet the needs of individuals and their families and caregivers. 3. Providers have increased capacity to deliver high-quality palliative care.
<p>Next Steps</p>

² The staffing model is outlined in a [technical paper](#) in the *Journal of Palliative Medicine* and in [summary](#) by the CSPCP.

- **Encourage adoption of the Ontario Palliative Care Competency Framework, including embedding minimum competencies into funding agreements with providers of palliative services.**
- **Explore best practice models that integrate palliative care training and education for interdisciplinary teams and others (support staff, volunteers, caregivers, etc.), including communication skills, and advocacy training, and culturally sensitive care as core competencies.**

Examples of existing resources:

- [The OPCN Palliative Care Competency Framework](#)
The Competency Framework outlines the knowledge and skills required by those caring for individuals with serious illnesses and their family caregivers, and by those specializing in palliative care. It can be used as a reference guide to inform curriculum development for healthcare providers and volunteers involved in providing palliative care.
- [CAPACITI](#) (Community Access to Palliative Care via Interprofessional primary care Teams Improvement Project)
Interprofessional primary care team practices participate in training modules as part of an implementation/quality improvement study to operationalize an early palliative care approach.
- [LEAP \(Learning Essential Approaches to Palliative Care\) Courses](#)
Pallium Canada has developed a suite of courseware on palliative care for health care organizations and professionals. The courses provide practical, inter-professional and evidence-based training in the palliative care approach.
- [PACE \(Palliative Care Education\) for Personal Support Workers](#)
Hospice Palliative Care Ontario and the Canadian Hospice Palliative Care Association (CHPCA) developed PACE for Personal Support Workers and Residence Support Aids to provide a palliative approach to care for adults residing in long-term care homes.
- [Indigenous Cultural Safety Training: Advanced illness, palliative care and grief](#)
Developed by the Canadian Virtual Hospice working in close collaboration with Indigenous and program leads across Canada, these courses aim to support Indigenous peoples, their families, friends, and members of their community.
- [A Palliative Approach to Care in the Last 12 Months of Life \(2020\)](#)
This best practice guideline (BPG) from the Registered Nurses' Association of Ontario (RNAO) provides evidence-based recommendations to nurses and the interprofessional health team who support adults (18 years and older) experiencing the last 12 months of a progressive life-limiting illness, their families and their caregivers.

- [Communication at End-of-Life eLearning Courses](#)
Developed by the Ontario Centres for Learning, Research and Innovation hosted at the Bruyère Research Institute and Algonquin College to help refresh or develop team members’ communication skills to provide quality end-of-life and palliative care in long-term care homes.
- **Paediatric Project ECHO – Palliative Care**
This [program](#) brings together community health care providers involved in caring for children and families with palliative care needs with PPC specialists for monthly “ECHO clinics”.
- **Education in Palliative & End-of-Life Care (EPEC) for Pediatrics**
EPEC for Pediatrics is a comprehensive adaptation of the EPEC curriculum designed to address the needs of children, their families and other pediatric clinicians.

4. Integrated Care

To address an individual’s full range of needs, palliative care should be introduced early and integrated with chronic disease management throughout the illness trajectory. Aligning with the goals of integrated care delivery through Ontario Health Teams, 24/7 palliative care requires barrier-free communication and coordination between members of the interdisciplinary care team and across settings to improve access, ensure smooth transitions, and facilitate continuity of care.

Goals
<ol style="list-style-type: none"> 1. Models of care for palliative care in hospitals, and an integrated model of care for pediatric palliative care across all care settings, are developed. 2. Models of care for palliative care in hospitals and the community, including long-term care homes, as well as for pediatric palliative care, are implemented. 3. Models of care for palliative care in hospital and community care settings, including long-term care homes, and the pediatric palliative care model of care, are monitored and evaluated to ensure they address barriers to integrated palliative care for individuals and their families and caregivers, along with their sustainability.
Next Steps
<ul style="list-style-type: none"> • Encourage the development of partnerships and linkages among regional care providers (e.g. among health service providers within Ontario Health

Teams), building inter-professional teams that use a lens of inclusion and cultural competency.

- **Conduct a comprehensive assessment to identify the supply of and demand for palliative care at both the provincial and regional level to support decision-making and system planning.**
- **Utilize resources for enhanced, barrier free communication between providers and palliative care recipients where appropriate, and in a variety of linguistic, cultural, and accessible formats.**

Examples of existing resources:

- [The OPCN Palliative Care Health Service Delivery Framework](#)
Describes a model of care with 13 recommendations, that will enable adults with a life-limiting illness who are living at home or in community settings (including long-term care homes), and their family/caregivers, to remain at home as long as possible.
- [RELIEF: A remote, self-monitoring app for palliative care](#)
Individuals receiving palliative care report their symptoms (e.g., pain and distress), through a web application on their computer or mobile device. Alerts are sent to care providers when symptoms become severe prompting a tele-health assessment and appropriate follow up.
- [PEACH \(Palliative Education and Care for the Homeless\)](#)
Led by Inner City Health Associates (ICHA), PEACH develops resources and operates a mobile unit to provide care to meet the needs of individuals who are homeless or vulnerably housed and have a serious illness.
- [Sick Kids Paediatric Advanced Care Team \(PACT\)](#)
PACT has cultivated partnerships with local palliative care providers across the region that it serves. Local physicians and nurse practitioners providing PPC have 24/7 access to PACT for real-time support and mentorship. A PACT nurse practitioner acts as the bridge between SickKids and the community, joining every initial home visit (in-person or virtually) for end-of-life care to ensure a smooth transition from hospital.
- [Pediatric Oncology Group of Ontario \(POGO\) Pediatric Interlink Community Cancer Nurses](#)
These nurses understand the challenges of families whose children have cancer. They move with the child and family between hospital, school, community and the home, and serve as the critical connection for accessing the support they need at all stages of cancer care.

5. Person-and Family-Centred Care

Palliative care should be aligned with the unique needs, wishes, goals, and values of individuals, their families, and caregivers. Individuals with a serious illness should receive care that is directed by their rights, dignity, and cultural diversity while also addressing their full range of needs across all domains. Person-centred care ensures health care providers work together with the individual and their family and caregivers as partners throughout their illness, through death, and into bereavement. Ensuring that Ontarians are aware of the value and benefits of palliative care and the resources available to support them, can empower them to engage in discussions about palliative care, and to play an active role in their care planning and management.

Goals
<ol style="list-style-type: none">1. Gaps to address the unique needs of individuals, as well as families and caregivers are identified.2. Best practices and mechanisms/processes that ensure care is person- and family -centred are leveraged or developed.3. Best practices and mechanisms/processes that ensure care is person- and family -centred are scaled and spread.
Next Steps
<ul style="list-style-type: none">• Identify individuals and their families and caregivers as central to palliative care delivery; ensure their cultural diversity is respected during assessments and care planning, including consideration of age-specific needs.• Utilize existing resources and best practices to assess and support the unique needs and capacity of caregivers and family members.• Examine how equitable access to bereavement supports and services can be established.

Examples of existing resources:

- [The Quality Standard for Palliative Care](#)
Quality statements including one pertaining to development of person-centred care plans as part of high-quality palliative care. Through an accompanying [Recommendations for Adoption](#) document, further support on implementation of the quality statements is available.
- [OPCN Palliative Care Health Services Delivery Framework](#)
Description provided above.

- **Hospice Palliative Care Ontario’s Hospice Standards**
Hospice specific standards set for governance, operations, patient care, and caregiver support to ensure quality and consistency in hospices across the province is in alignment with the Quality Standard for Palliative Care.
- [Speak Up Ontario Resources](#)
These resources provide guidance for individuals and families, health care providers and non-health care professionals around advance care planning, health care consent, goals of care discussions, and substitute decision makers.
- [Palliative Care Toolkit for Indigenous Communities](#)
This toolkit includes resources and reference material for First Nations, Métis and Inuit families and communities. It can be used to help support people with cancer or other serious illnesses who have palliative care needs. These educational materials can be used by anyone in the community.
- [Ontario Caregiver Organization](#)
This organization provides resources, education, supports, as well as reports and research for family caregivers, health care providers, volunteers, and employers.

6. Evidence and Data

High-quality palliative care requires data systems to support ongoing system planning, quality improvement, research, evaluation and decision-making. Organizations can participate in shared learnings to facilitate equitable access between diverse and underserved populations. Data and research should respect Indigenous data governance principles such as the First Nations Principles of OCAP® (ownership, control, access, and possession).

Goals
<ol style="list-style-type: none"> 1. Existing data resources are reviewed and current gaps are identified in order to inform performance measurement. 2. Data collection processes are planned, coordinated and standardized. 3. Palliative care evidence is applied and promoted, and data collection processes are implemented to inform and support planning, policy decisions and government directions about palliative care.
Next Steps
<ul style="list-style-type: none"> • Support ongoing measurement and management of palliative care performance indicators at the regional and provincial level.

- **Use data to support system and capacity planning and to inform regional allocations of resources.**
- **Implement performance measurement strategies to inform planning decisions, quality improvement, and evaluation, including consideration for individual and caregiver reported experience measures.**

Examples of existing resources:

- **OPCN Provincial Indicators**
Three reporting products are made available regularly (quarterly or annually) to enable measurement of progress of palliative care delivery for the adult population against the [OPCN Action Plan 1](#) and [Action Plan Priorities for 2021/2022](#), and to support planning decisions at provincial, regional and sub-regional levels.
- [The Quality Standard for Palliative Care](#)
For each of the 13 quality statements included in the Quality Standard for Palliative Care, indicators are proposed in areas of process, structure, and/or outcome, which can help clinicians and organizations to assess care quality and identify gaps and opportunities for improvement.
- **Caregiver Voice Survey (CVS)**
The survey is an experience measure completed by a caregiver or family member upon death on behalf of an individual who received palliative care. Respondents reflect on experiences on end-of-life care provided and supports received for the adult population.
- **Data Sub-Committee of the PPPC-SC**
This group has begun some foundational work to define, describe and create an essential data set for pediatric palliative care.

7. Public Awareness

Improving the public’s general understanding of palliative care, the role of services, and available supports for individuals and their families and caregivers are important for reducing stigma, normalizing death and dying, as well as empowering individuals to access palliative care services, and manage their care. Increasing public awareness can strengthen an individual’s autonomy as they become informed about available health care options.

Goal
1. Ontarians are informed about palliative care, what it entails, and where to access resources, tools and information when needed.

Next Steps

- **Support conversations among health care providers, individuals, families, and caregivers about palliative supports and services.**
- **Identify opportunities, through existing and emerging partnerships and across multiple levels of government, to advance a public-health approach to palliative care in the province.**

Successes that could be leveraged:

- **Compassionate Communities**

Hospice Palliative Care Ontario [is leading the Ontario Compassionate Communities Provincial Strategy](#). Through community partnerships, compassionate communities increase awareness and create social support networks around those with long term illness or coping with grief and loss. The model provides for early detection of palliative care needs, addresses the unmet needs of adults who fall through the cracks of regular systems because of poverty, isolation or other social determinants of health.

- [Canadian Virtual Hospice](#)

This online platform provides support and personalized information about advanced illness, palliative care, loss and grief specific to different audiences (e.g. family members, health care providers, educators or researchers), and also includes content and topics focused specifically on Pediatric Palliative Care.

PART III - Implementation and Next Steps

Implementation

Given the cross-sectoral nature of palliative care in Ontario, and the number of stakeholders and partners involved in driving improvements in palliative care delivery, no one organization or entity can take sole responsibility for moving the Framework forward. Collaborations will be necessary among all those involved in the sector, including, relevant ministries, Ontario Health, Ontario Health Teams, health care and other service providers, individuals, and caregivers.

The Ontario government is building a connected health care system centred around patients, families, and caregivers. These changes will strengthen local services, making it easier for patients to navigate the system and transition among providers, including those who provide palliative care.

Ontario Health Teams are being introduced to provide a new way of organizing and delivering care that is more connected to people in their local communities. Under Ontario Health Teams, health care providers (including hospitals, physicians and home and community care providers) work as one coordinated team, no matter where they provide care. As Ontario Health Teams develop, they will partner with a range of organizations to provide person-centred care.

Ontario Health Teams are ideally suited to support implementation of the Framework set forth in this report, because they are already delivering integrated, interdisciplinary care. The tools and guidance developed by the Ontario Palliative Care Network, and the expertise of the regional partners will be important resources to support them in this work.

The pandemic has also highlighted that further efforts are required to strengthen access to high-quality palliative care in long-term care homes. Ontario is working to address service gaps and to strengthen accountability for the quality of care provided to these individuals.

Implementation of the Framework is expected to result in improved access to palliative care for both the pediatric and adult populations in the province. Individuals with a serious illness will have their palliative service needs identified early, and providers will be prepared and supported to provide high quality care. Integrated palliative care will be delivered by interdisciplinary care teams to individuals (children or adults) when and where palliative care is preferred and/or required.

The Framework will enable a health care system that serves the palliative needs of all Ontarians, including children, First Nations, Inuit, Métis, and urban Indigenous communities, racialized communities, Francophones, 2SLGBTQQIA+ Ontarians, as well as other culturally diverse and underserved populations. All Ontarians, irrespective of age or where they live, will have equitable access to palliative care that is timely, coordinated and available in their preferred settings. All Ontarians will benefit from a health care system that is person and family-centred, one that achieves better outcomes throughout the course of a serious or life-limiting illness, and one that is more cost effective.

Evaluation

The Minister of Health is required to submit a report on the state of palliative care to the Legislative Assembly three years from the time of submission of the Framework (December 2024). To support development of this report, system planners can continue to refer to existing Provincial Palliative Care Indicator Reports made available by the OPCN. Through system and supporting-level measures, these reports can aid in progress measurement, enable peer comparison, guide quality improvement activities, and support capacity planning.

While the Ontario Palliative Care Network has established system-level measures to support performance measurement and management for the adult population, similar system level measures do not exist for pediatric palliative care. The Ministry will work with its partners to develop an evaluation approach for this population.

Overall, system level measures for palliative care can help track palliative care transformation as new programs and quality improvement initiatives are introduced locally, regionally, and provincially.

Conclusion

The path forward to implement the Framework is complex and requires the Ministry of Health's collaboration with all interested parties, including individuals with a serious illness and their families and caregivers, academia, health care delivery organizations, long-term care homes, health professional groups, community and social service organizations, and all levels of government. As this important work progresses, the ministry is committed to working with our partners to address the palliative care needs of Ontarians.

Appendix: Glossary of Terms

Advance Care Planning

In Ontario, advance care planning is an iterative process that involves the mentally capable individual: Identifying their future substitute decision-maker who can make certain types of decisions about the individual's care when and if the individual becomes incapable of making the decision by:

- considering who would be their default/automatic substitute decision-maker(s) in the substitute decision-maker hierarchy list in the *Health Care Consent Act, 1996* with respect to decisions about treatment, admission to a care facility (currently applicable only to long-term care homes), or personal assistance services (currently only in a long-term care home); and
- deciding whether to choose someone to act as substitute decisionmaker by executing a Continuing Power of Attorney for Personal Care (a formal written document).

Sharing their wishes, values, and beliefs through conversations with the persons who will or may be substitute decision-makers and others that clarify their wishes, values and beliefs, and more generally, how they would like to be cared for in the event of incapacity to give or refuse consent. Rather than being a single event, advance care planning is ongoing and dynamic, with the potential for personal preferences to change over time as health status changes. It may be initiated at any point in the health care process, and may involve individuals who are currently healthy.^{ix}

Bereavement

Bereavement is the state of having experienced and being in the period of mourning after a loss, such as a death. It may refer to a specific time, such as a timeframe set out in employment bereavement leave benefits, and/or may refer to rituals in cultures or religions.^x

Caregiver

A caregiver is an unpaid person who provides care and support in a nonprofessional capacity, such as a family member, a friend, or anyone else identified by the person with a serious illness. Other terms commonly used to describe this role include care partner, informal caregiver, family caregiver, carer, or primary caregiver.^{xi}

Competencies

Competencies refer to the range of knowledge, personal attributes, and skills that enable the behaviours needed to effectively perform a role within an organization.^{xii}

End-of-Life Care

End-of-life care focuses on preparing for an anticipated death of the individual (child or adult), and managing the end stage of a serious illness. This includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both the individual (child /young person/adult) and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.^{xiii}

Family

Family consists of those closest to a person in terms of knowledge, care, and affection, and may include biological family (i.e. parents, grandparents, and siblings), family through marriage, or family of choice and friends. The person with the serious illness defines their family and who will be involved in their care.^{vi}

Health Care Provider

A health care provider is a person that provides a health care service. This term is broader than health care professional, and may also include individuals providing health care services that are not regulated in Canada (e.g., personal support workers, also known as health care aides and a number of other titles across Canada). While health care providers are usually paid for providing health care services, a comprehensive definition could also include volunteers.^v

Hospice

A hospice is a community-based organization (or a program offered by a multi-service organization) that provides support to individuals living with a serious illness and their caregivers, family members, and friends.⁸ Support is provided to the service recipient in a variety of settings, including where the individual lives or in a homelike setting. The goal of hospice care is to enhance the quality of life of the individual and the well-being of anyone that is impacted by the person's illness or death. Volunteers play an integral role in achieving that goal. A hospice provides services such as hospice-trained volunteers, day programs, psychosocial supports, grief and bereavement support, spiritual care, caregiver support, wellness programs, complementary therapies,

children's programs, outreach/shared care teams, and end-of-life care within a residential hospice.^{xiv}

Goals of Care Discussion

A discussion between an individual (or the individual's Substitute Decision Maker if the individual lacks capacity) and healthcare provider(s) that addresses the individual's goals for the individual's care in the context of healthcare consent and decision-making in advanced illness. The purpose of these discussions is to outline the individual's values, beliefs, wishes, perception of quality of life and what the individual characterizes as meaningful and important. Other elements include the individual's understanding of current health conditions, prognosis, and likely course of events if the individual's goals of care are applied to potential treatment decisions. The goals of care discussion provides the foundation for decision-making and will often include the development of (and obtaining informed consent to) a plan of treatment.^{iv}

Interdisciplinary Palliative Care Team

An interdisciplinary palliative care team is a group of providers that works together to deliver palliative care to an individual and their family and caregivers based on the individual's care plan. This team will consist of a most responsible medical provider (physician or nurse practitioner) and a designated care coordinator and will have an established connection with a palliative care specialist(s) whose role on the team will be to consult with team members and to provide direct patient care as needed. The team will often be expanded to include additional providers, for example, nurses, disease specific specialists, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, Indigenous providers and volunteers.^{xv}

Interprofessional

Interprofessional describes the relationship between various disciplines as they interact to work purposefully and learn together to achieve a common goal. For example, if a client has trouble swallowing, nurses, speech language pathologists and dietitians need to work together as a team to figure out what is wrong and how to help the client.^{xvi}

Long-Term Care Home

Long-term care homes provide residential accommodation and care to individuals 18 years of age and older who require, at frequent intervals throughout the day, assistance with activities of daily living, and/or on-site supervision or on-site monitoring to ensure the individual's safety or well-being, and/or who requires nursing care available on site 24/7.

Ontario Health Team

An Ontario Health Team is a group of providers and organizations that are clinically and fiscally accountable for delivering a full and coordinated continuum of care to a defined geographic population.

Primary Care

Primary care is the first point of contact between an individual and the health care system and includes illness prevention, health promotion, diagnosis, treatment, and rehabilitation and counselling.^{xvii}

Residential Hospice

A residential hospice is a health care facility and registered charity that offers palliative care services by an inter-professional team with palliative care expertise. Care is available 24 hours a day, 7 days a week in a home-like setting for the individual and their significant others.^{xviii}

Respite Care

Respite care may be a setting of care, a program or a service that provides additional services. Respite care may take place in the individual's home or in a setting outside of the home such as a hospital, long-term care facility or hospice.^{xix}

Retirement Home

A retirement home is a privately-owned residence that provides rental accommodation with care and services for seniors who can live independently with minimal to moderate support and who are able to fund this lifestyle on their own.

The resident (or family) pays for the accommodation and services provided within the retirement community. Sometimes a subsidized bed may be available through the municipal government for those who need care. Should home care services be required, publicly funded services may be available through Home and Community Care Support Services.

Retirement homes are regulated by the Retirement Homes Regulatory Authority in accordance with the *Retirement Homes Act, 2010*.

Underserved population

The underserved populations include First Nations, Inuit, and Métis peoples, pediatric populations, people who do not speak either of Canada's official languages, people with

alternate sexual orientation, immigrants, refugees, ethnically or racially diverse populations, people with disabilities, the homeless, sex trade workers, and people with low incomes.^{xx}

Appendix: Acronyms

2SLGBTQIA+ 2-Spirit (Two-Spirit), lesbian, gay, bisexual, trans, queer, questioning, intersex, and asexual orientations

24/7 Twenty-four hours a day and seven days a week

CAPACITI Community Access to Palliative Care via Interprofessional Primary Care Teams Improvement Project

CCA Compassionate Care Act

CHPCA Canadian Hospice Palliative Care Agency

CSPCP Canadian Society of Palliative Care Physicians

LEAP Learning Essential Approaches to Palliative Care

Ministry Ministry of Health

MPP Members of Provincial Parliament

OAGO Office of the Auditor General of Ontario

OH Ontario Health

OPCN Ontario Palliative Care Network

POGO Pediatric Oncology Group of Ontario

PPC Pediatric Palliative Care

PSW Personal Support Worker

RIWG Regional Implementation Working Groups (of the Provincial Pediatric Palliative Care Steering Committee)

RPCN Regional Palliative Care Networks

The Declaration Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action

Appendix: References

- ⁱ Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action [Internet]. Queen's Printer of Ontario; 2013. Accessed at: http://health.gov.on.ca/en/public/programs/lc/docs/palliative%20care_report.pdf
- ⁱⁱ Kelley, A. S., & Bollens-Lund, E. (2018). Identifying the Population with Serious Illness: The "Denominator" Challenge. *Journal of palliative medicine*, 21(S2), S7–S16. <https://doi.org/10.1089/jpm.2017.0548>
- ⁱⁱⁱ Government of Ontario (2021). *Ontario Population Projections*. <https://www.ontario.ca/page/ontario-population-projections>
- ^{iv} Auditor General of Ontario (2014). 2014 Annual Report of the Office of the Auditor General of Ontario. Chapter 3.08, Palliative Care. Accessed at: http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf
- ^v Canadian Institute for Health Information (2018). *Access to Palliative Care in Canada*. <https://www.cihi.ca/en/access-to-palliative-care-in-canada>
- ^{vi} The Change Foundation & The Ontario Caregiver Organization. (2019). 2nd Annual Spotlight on Ontario's Caregivers: 2019. Available from: [Spotlight-on-ontarios-caregivers-2019 EN.pdf](https://www.change.org/spotlight-on-ontarios-caregivers-2019)
- ^{vii} First Nations Advisory Committee on Home and Community Care (2017). Home and Community Care in First Nations Communities in Ontario. Available at https://www.lco-cdo.org/wp-content/uploads/2019/03/Final_Report_of_the_First_Nations_Advisory_Committee_on_HCC_-_June_2_2017.pdf
- ^{viii} Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: care of the patient requires care of the provider. *Annals of family medicine*, 12(6), 573–576. <https://doi.org/10.1370/afm.1713>
- ^{ix} Ontario Palliative Care Network. Key palliative care concepts and terms [Internet]. Toronto: The Network; 2017. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/KEY_PALLIATIVE_CARE_CONCEPTS_AND_TERMS.pdf
- ^x Health Canada. (2018). Framework on Palliative Care in Canada. Ottawa, Canada. Available from: <https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf>
- ^{xi} Health Quality Ontario. Quality Standards. Palliative Care: Care for Adults with a Progressive, Life-Limiting Illness [Internet]. Toronto (ON): Queen's Printer for Ontario; 2018. Available from: <https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf>.
- ^{xii} Lucia, A.D., & Lepsinger, R. (1999). The art and science of competency models: Pinpointing critical success factors in organizations. San Francisco: Jossey-Bass/Pfeiffer.

^{xiii} Accreditation Canada. Hospice, Palliative, End of Life Services Standards, version 11, For Surveys Starting After: January 01, 2017. Ottawa (ON); 2016

^{xiv} Hospice Palliative Care Ontario. Standards for visiting hospice services. Toronto: The Organization; 2014 May.

^{xv} Ontario Palliative Care Network. Palliative Care Health Services Delivery Framework: Recommendations for a Model of Care to Improve Palliative Care in Ontario, Focus Area 1: Adults Receiving Care in Community Settings. Toronto (ON): The Network; 2018. Available: <https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/2021-01/OPCNHSDFRecommendations.pdf>

^{xvi} Education. University of Toronto [Internet]. 2008. Available from: <http://www.sjcg.net/departments/education/faq.aspx>

^{xvii} Primary Care Payment Models in Ontario. Ministry of Health and Long-Term Care [Internet]. 2017 Available from: <http://www.health.gov.on.ca/en/pro/programs/pcpm/>

^{xviii} Hospice Residence. (2021, Aug). In *Ontario Palliative Care Network: Who Provides Palliative Care and Where*. Retrieved from <https://www.ontariopalliativecarenetwork.ca/about-palliative-care/who-delivers>

^{xix} Canadian Hospice Palliative Care Association, Ottawa, Canada. (2006). Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice. Available from: https://www.chpca.ca/wp-content/uploads/2019/12/Pediatric_Norms_of_Practice_March_31_2006_English.pdf

^{xx} Health Canada. (2001). Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada (Catalogue no. H39-618/2002E)